“Man in the driving seat”

Psycho-Oncology
Journal of the Psychological, Social and Behavioral Dimensions of Cancer

'Man in the driving seat': a grounded theory study of the psychosocial experiences of Black African and Black Caribbean men treated for prostate cancer and their partners

Journal:	*Psycho-Oncology*
Manuscript ID	PON-19-0160.R2
Wiley - Manuscript type:	Paper
Date Submitted by the Author:	30-May-2019
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Keywords:	Cancer, Oncology, Black African, Black Caribbbean, Experiences, Grounded theory, men, partners, prostate cancer, psychosocial

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Short title: The experiences of Black men treated for prostate cancer and partners

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Abstract

Objective: Evidence suggests that treatment side-effects of prostate cancer (CaP) substantially affect the psychosocial well-being of affected men and their partners. However, this phenomenon is poorly understood among high risk (1 in 4) Black African (BA)/Black Caribbean (BC) men and their partners as they are currently under-represented in global research on CaP survivorship. This study explored the psychosocial experiences of BA/BC men with CaP and their partners in the United Kingdom as they lived through the side-effects of CaP treatment within their own socio-cultural and marital contexts. **Methods:** Using constructivist grounded theory methodology, interviews and focus groups were conducted with eligible men (n=25), partners (n=11) and healthcare professionals (HCPs) (n=11) recruited in England. Data were iteratively analysed using constant comparison following the key stages of initial, focused and theoretical coding until saturation was achieved. **Results:** Data analysis culminated in the development of a substantive theory '*man in the driving seat*' which describes the experiences of BA/BC men with CaP and their partners within their context. Culturally informed gender roles and identities influenced how men and partners responded and coped with the side-effects of CaP treatment. There was a hierarchy of power within the BA/BC relationship in which men were dominantly positioned as leaders, whilst partners mostly operated from a supportive but 'accepting' position. **Conclusion:** Inclusive and culturally sensitive individual and couple-focused psychosocial support which is devoid of stereotyping and recognises the experiences of both BA/BC men and their partners is recommended.

Keywords: Black African, Black Caribbean, experiences, grounded theory, men, partners, prostate cancer, oncology, psychosocial

Background

The disproportionately high risk (1 in 4) of prostate cancer (CaP) at a younger age, in more aggressive forms and advanced stages among Black African (BA) and Black Caribbean (BC) men compared with Caucasian (1 in 8) men[1] suggests that they may be more adversely affected by its treatment side-effects (such as sexual dysfunction, incontinence, fatigue). Evidence suggests the existence of cultural disparities in the psychosocial impact of CaP treatment side-effects[2] on affected men and their partners, either as individuals[3,4] or as a couple[5,6].

This phenomenon is poorly understood for higher risk BA and BC populations due to their under-representation in global psychosocial research on CaP survivorship. The majority of studies in this area have predominantly focused on Caucasian groups[7-9]. The few studies involving Black men have either focused on African-American [10] or older Jamaican[11] men. Research which has explored partners' experiences in this racial group is even scarcer. Disparities in demographic and socio-cultural settings between the United States (US) and the United Kingdom (UK) coupled with intricate cultural differences among the different ethnic members of the Black racial group, suggest that evidence from studies on African-Americans may not reflect the exact experiences of UK-based BAs/BCs.

Predominant perceptions of stigma associated with CaP[12], hierarchical power structure in marital relationships[13] and traditional gender values which are underpinned by hegemonic masculinity stereotypes[13] also suggest the post-treatment experiences of BA/BC men with CaP and their partners may be different. In addition to male dominance, independence and stoicism which all characterise hegemonic masculinity[14], there are societal expectations in some BA/BC cultures for the man to be the natural head of the family, taking on roles such as the main breadwinner and decision-maker;[15, 16] while the woman's role is more associated with dependence and care-giving[15]. Associating idealistic masculine identity of BA/BC men with sexual virility and performance[16, 17] further hints at the potential impact of treatment-related sexual dysfunction on the psychosocial wellbeing of couples within this cultural context.

As global healthcare priorities increase towards improving cancer care and survivorship[18], it is pertinent to recognise ethnic disparities in CaP risks, experiences and psychosocial outcomes. This

could help to ensure that clinical services are complemented with culturally sensitive psychosocial support to promote holistic recovery and improved quality of life for men and their partners after CaP treatment[19, 20]. Engaging under-researched BA/BC men with CaP and their partners in exploratory research could facilitate increased understanding of their post-treatment experiences. Therefore, this study explored the psychosocial experiences of BA/BC men with CaP and their partners in the UK as they lived through the side-effects of CaP treatment within their own socio-cultural and marital contexts.

Methods

Study design

Charmaz's constructivist grounded theory design[21] guided the conduct of the study. This involved co-construction of knowledge between the researcher and study participants to better understand participants' experiences after CaP treatment. The study is reported following the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines[22].

Sampling and recruitment

Prior to theoretical sampling, convenience and snowball sampling were used to access participants who provided the preliminary data which directed subsequent interviews[21]. Between October 2016 and March 2018, eligible men and partners (Table 1) were recruited in England by collaborating with three NHS Trusts, a prostate support group, networking with researchers' colleagues, and snowballing through research participants. A detailed discussion on recruitment has been published elsehwere[23]. Emerging themes from the initial analysis of the men's and partners' data suggested the inclusion of healthcare professionals (HCPs) in the study (theoretical sampling). For example, preliminary analysis of men's and partners's data identified a lack of recognition for their unmet support needs by HCPs. HCPs ~~wre~~ recruited through three NHS Trusts in England.

Data collection

Individual interviews and focus groups (HCPs only) facilitated data triangulation across the men's, partners' and HCPs' perspectives in order to generate rich and in-depth data[24]. Semi-structured topic guides with open-ended questions informed by the literature and study participants were developed and piloted. Sample questions included the experience of being treated (men) or being a partner to someone treated for CaP, and impact of treatment side-effects on self and marital relationship. The topic guides were iteratively modified after the initial interviews in line with theoretical sampling procedures[21]. Each participant was privately interviewed by the first author (OB), a BA woman in her mid-thirties who had no prior relationship with them. The audio-recorded interviews lasted between 30–90 minutes and were either held at each participant's home, place of work, or by Skype or telephone. The two focus groups with HCPs were held at their respective Trusts and co-facilitated by the first (OB) and last (EM) authors. Each focus group was audio-recorded and lasted between 30-45 minutes.

Ethical approvals and considerations

Ethical approvals were obtained from Ulster University (REC/16/0079), Health Research Authority (17/YH/0027) and participating NHS Trusts. Written informed consent was obtained from each participant. Transcripts were anonymised (using pseudonyms) to protect participants' confidentiality.

Data analysis

Interview and focus group transcripts were organised and managed with NVivo 11 software. Data were analysed using constant comparison which involved iteratively comparing codes, emergent categories and reflective memos with further data until theoretical saturation was achieved[21] (Figure 1). Data were independently analysed by four authors (OB, HM, BML and EM). Differences in opinion were resolved through discussion. Keeping reflexive and analytical memos enhanced theoretical sensitivity whilst theoretical sampling enhanced the validation of emerging categories and the substantive theory developed[21].

Results

Overview

Theoretical saturation was achieved after 38 interviews and two focus groups (consisting of five and four HCPs respectively). A total of 25 men, 11 partners and 11 HCPs (n = 47) participated in the study (Table 2). The substantive theory developed (Figure 2) was made up of one core category '*man in the driving seat'* and four related categories from the three data sets: '*owning the illness'*, '*navigating the journey through a bumpy terrain*', '*partner in the passenger seat*' and '*healthcare professionals recognising the difference'*.

Category one: owning the illness

Findings showed that BA/BC men owned their CaP illness from diagnosis through treatment and post-treatment. Men highlighted that as it was their own bodies affected by CaP, they felt responsible for taking care of themselves and the decisions related to their illness, minimally involving their partners.

Men's autonomy in decision-making was particularly reflected in the area of public disclosure. Amidst conflicting views regarding disclosure, most men kept their CaP illness private, and also restricted their wives from public disclosure. Some men described disclosure as a sign of weakness and admittance of vulnerability which was not consistent with their masculine identity to be stoic. A few men added that restricting disclosure enabled them to retain ownership over their personal information, and avoid cultural stigma often associated with cancer fatality and sexual impotence associated with CaP [Table 3, 1i]. However, some men argued that public disclosure of the CaP enabled them to overcome their own fear of cancer fatality and increased their awareness of additional strategies to cope with treatment-related fatigue and pain (e.g. supplementary therapies). Amidst disruptions caused by side-effects of CaP treatment (e.g. changes to usual daily routines), men's priorities included: taking charge of their lives, returning to pre-treatment normality and retaining control of their manly duties (e.g. 'earning money') [Table 3, 1ii].

Category two: navigating the journey through a bumpy terrain

Men received care and support from HCPs, with many reporting more positive comments than negative. Positive comments included: being given treatment options which allayed men's initial fears of cancer fatality, and having an empathetic and "*professional"* doctor [Table 3, 2i]. Negative experiences of healthcare were mostly attributed to later diagnosis (resulting in more intensive treatment and worse side-effects), lack of psychosexual support, and perceptions of dismissive behaviour and insensitive language used by some HCPs[Table 3, 2ii].

Dealing with the reality of post-treatment sexual dysfunction was particularly challenging for many of the men. Some felt discouraged by now having to deliberately 'prepare' for sex with clinical aids which they reported were sometimes ineffective. Such men navigated this challenge by viewing sex as a planned marital obligation rather than a spontaneous pleasurable activity[Table 3, 2iii]. Some men proactively explored alternative ways to achieve an erection without clinical aids (e.g. requesting a 'blow job' from their partner, which seemed to provide sexual pleasure but not erection).

Living with treatment side-effects became a new norm for men as they demonstrated a resilient attitude, reiterating they were grateful to be alive. They proactively adjusted their daily routines (e.g. having a bottle in the car for urinary urgency) and used distractions such as work to deal with the psychological challenges of treatment side-effects. Some men's resilience was enhanced by spiritual faith and prayers. Whilst many men were comforted in having had children prior to treatment, some expressed concerns over feelings of diminished masculinity due to the loss of their sexual virility[Table 3, 2iv]. Men with partners were encouraged by their partner's loyalty and support while single/widowed men received support from their children through regular visits/phone calls. Some men who had disclosed their diagnosis also received support from colleagues who had gone through a similar CaP experience, their employer, pastor and close church friends.

Category three: partner in the passenger seat

Findings showed that many of the partners felt isolated and excluded from their husband's CaP journey especially with regards to information, psychosexual support and marital communications. The women were distressed by their husbands' lack of recognition for the psychological impact the CaP

experience had on them as partners. Some women said their husbands autonomously took decisions on how they wanted to deal with their sexual problems without consulting with them (partners)[Table 3, 3i].

Women further expressed disappointment at the lack of professional support focused on partners within current healthcare. Women's psychological and emotional distress was also attributed to their feelings of financial insecurity if their husband died from the CaP, lack of couple-focused psychosexual support, and especially communication barriers with their husband regarding how treatment-related sexual dysfunction was impacting on their marital intimacy [Table 3, 3ii].

Although actively providing moral and practical support for their husbands through the CaP experience, partners reported their husband's restriction on public disclosure of the CaP limited the women having their own support network. The women mostly coped by prioritising their care-giving roles over own psychological and emotional needs, using distractions (e.g. work and childcare), feeling sympathetic and loyal towards their husbands and also by praying. A detailed discussion of partners' experiences has been reported elsewhere[25].

Category four: healthcare professionals recognising the difference

HCPs highlighted that from their clinical experience, BA/BC men appear to be culturally different from Caucasian patients in their attitude and response to CaP. Some HCPs noted young Black men often delayed receiving medical treatment for their CaP, thereby resulting in advanced cancers at final treatment. HCPs added that whilst psychosexual counselling services may be lacking in current post-treatment routine care, clinical aids are often offered to help men deal with treatment-related sexual dysfunction. HCPs reported that Black men were often reluctant to embrace such aids as they seemed to take pride in their ability to achieve natural potency[Table 3, 4i]. HCPs further narrated that in contrast to Caucasian patients, BA/BC men were often reluctant to involve their partners in their CaP journey. When probed by HCPs, some BA/BC men highlighted a personal responsibility to handle their CaP themselves and 'protect' their partners from their illness experience. Some HCPs also perceived that some BA/BC men's preference to exclude their partners from the CaP journey may be to avoid being seen as 'less of a man' due to loss of sexual virility post-treatment[Table 3, 4ii].

The core category: man in the driving seat

The core category *'man in the driving seat'* provides useful analytical insights into why BA/BC men needed to 'own their illness' while their partners occupied a peripheral position along the CaP journey. The reasons seemed to be tied to the men's desire to resist the 'emasculating' tendency of CaP to strip them of their culturally-informed masculine roles and identity Table 3, 5i, 5ii. There appeared to be a hierarchy of power within the BA/BC relationship in which the men were dominantly positioned as leaders, whilst their partners mostly operated from a supportive and 'accepting' position. Triangulation of the three data sets highlighted an autonomous behaviour from most of the men about taking up CaP treatment and managing its side-effects Table 3, 5iii, 5iv, 5v.

The gendered definitions of BA/BC men's and partners' roles as depicted in '*man in the driving seat*' also seemed to have contributed to the observed differences in their understanding of each other's priority needs after CaP treatment, despite being married for more than ten years. Whilst a few of the men recognised the need for their partners to have support, the majority seemed oblivious of how their partners were impacted by the CaP experience or what the women's specific support needs were. Some men's perceptions were that their partners were strong and coping well, primarily drawing strength from supporting the men Table 3, 5vi, 5vii.

There were communication challenges among couples in discussing the man's sexual problems and its impact on their intimate marital relationship. Some men reported avoiding such discussions so as not to be perceived as weak; while others admitted avoiding the subject because they did not know what to say. This resulted in despondent feelings for the men and frustration for their partners Table 3, 5viii, 5ix. Nearly all the men articulated sexual recovery as their priority need. They identified the need for professional psychosexual support to help them self-manage their sexual problems without appearing emotionally weak. Despite men's portrayal of 'machoism', findings suggest that being in the '*driving seat*' can be isolating and physically/mentally challenging for them due to cultural expectations associated with their masculine roles. Although men were not happy with the challenges CaP posed to them, they ~~felt~~ pressured ~~(by themselves)~~ to suppress such feelings Table 3, 5x.

Discussion

This study explored the psychosocial experiences of BA/BC men with CaP and their partners in the UK as they lived through the side-effects of CaP treatment within their own socio-cultural and marital contexts. Findings indicated that most of the post-treatment experiences of men (e.g. feelings of diminished masculinity due to post-treatment sexual dysfunction) and partners (e.g. communication barriers to discussing sexual concerns) in this study mirrored previous reports on Caucasian[7, 8] and African-Americans[26] groups. An intersection of clinical treatment procedures, physical side-effects of CaP treatment and common gender stereotypes regarding masculinity may have contributed to these similarities.

However, it appeared that a higher prevalence of CaP among younger BA/BC men coupled with hegemonic masculinity beliefs which are predominant within their cultural context may have contributed to some differences observed in how they and their partners responded to the CaP experience. For example, couples experienced post-treatment sexual problems at an age where sex is a priority in their relationship. The influence of age on men's enactment of their masculinity has also been recognised within the literature[27]. The assumption is that younger men often exhibit greater self-independence than older men[27]. Such an assumption coupled with perceptions that they were the ones directly affected by the physical symptoms of treatment side-effects may have further contributed to the self-dependent behaviour of BA/BC men in this study as most of them were aged 65 years or less. Comparable findings from a previous study[11] showed a similar trend among their younger BC participants who reported asking questions and seeking additional information before making treatment decisions, unlike the older men (> 75 years old) who expressed an 'accepting' behaviour towards treatment recommendations from their doctors.

The economic impact of CaP on a man's role as the breadwinner also seemed more pronounced among the younger men in this study as they were still in their productive work years at diagnosis and treatment. The older men appeared less psychologically affected by the impact of CaP on their breadwinning role possibly because some had older children who were already financially independent and seemed to have other fewer financial obligations. Men's access to free healthcare through the UK-NHS in this study also suggest that their masculinity concerns regarding the financial

impact of CaP may be different from that of other Black men resident in countries without free healthcare and who may have to self-fund their cancer treatment (e.g. African-Americans).

Avoiding discussions with partners about mutual ways of dealing with post-treatment sexual challenges has been similarly reported among Caucasian men with CaP[28]. However, evidence from this study suggests that cultural values for BA/BC men to take responsibility for themselves and others[29] may explain their preference for a solo approach to manage their CaP challenges without 'sharing the burden' or appearing vulnerable. Seminal literature on coping[30] identified this behaviour as 'protective buffering' which has been associated with elevated psychosocial distress among people living with chronic illnesses and their care-givers[31, 32]. Adopting active engagement[30] through open communications and shared problem-solving with partners could help men deal with the psychological distress associated with feelings of lessened masculinity[33] and also improve spousal adjustment to sexual dysfunction after CaP treatment[34].

The reference of men in this study to 'fatherhood' as a coping strategy also demonstrates their resilient determination to move on with life regardless of the perceived cultural implications of losing their sexual virility (effeminate). The chronic nature of inevitable treatment side-effects of CaP may have further compelled men in this study to prioritise being alive over idealistic construction of masculinity around sexual performance and reproductive ability[35,36]. Nevertheless, BA/BC men's independent and resilient behaviour in the face of a challenging illness highlights the existence of ingrained hegemonic masculinity beliefs which should not be undermined. There were no notable differences between the BA and BC men interviewed in this study as they mostly referred to themselves as Black men and it appeared they viewed their experiences from this broad racial lens. Whilst evidence suggests that shared racial origin does not imply shared ethnicity/culture[37], it appears that BA and BC men's shared beliefs regarding hegemonic masculinity and their similar demographics in this study (e.g. UK-based, age, treatment type, marital status) may have contributed to the resonance in their pattern of behaviour along the CaP journey. Mulugeta *et al*[12] also identified substantial similarities in the beliefs and attitudes of BA and BC men in the UK towards cancer.

Clinical implications

Findings suggest that complex intersections between high risk of CaP at younger age, treatment side-effects and socio-cultural constructions of gender role and identities, substantially influence the behaviour pattern of BA/BC men and their partners along the CaP journey. HCPs need to take these factors into consideration and avoid stereotyping in use of medical services by this population. Prioritisation of their reproductive and breadwinning roles, a reluctance towards public disclosure of their CaP and limited use of external support, also indicate that the psychological burden of BA/BC men after CaP treatment, should not be undermined. The impact of these on partners' experiences also needs to be acknowledged. In light of NHS England's objective to help patients to self-manage their health and care with professional guidance from HCPs[38], there is need to focus on co-producing psychosocial and psychosexual interventions and also provide relevant information which equip BA/BC men to self-manage their post-treatment symptoms in an appropriate way with men remaining in the 'driving seat'. Noting couples' difficulty in discussing post-treatment sexual concerns, HCPs could help to bridge such communication gaps by engaging the man and his partner as a unit when providing post-treatment psychosexual support for them.

Study limitations and directions for future research

The majority of men and partners in this study being younger, well-educated and in heterosexual marital relationships may have contributed to the observed homogeneity in their narratives. The influence of acculturation to a culturally different UK society on men's experiences is also unclear in this study. The possible effect of an individual's unique circumstances or personality type on shaping experience regardless of shared cultural beliefs further highlights the complexity of untangling the heterogeneity among BA/BC groups. Larger studies are needed to explicate heterogeneity within this population and identify how much of their CaP experiences can be attributed to age, marital status, ethnicity and acculturation.

Conclusion

Study findings suggest the experiences of UK-based BA/BC men with CaP and their partners mirror those of Caucasian groups. However, nuanced cultural differences existed in their responses and coping with the disease, which the substantive theory '*man in the driving seat*' may have helped to explicate. There is need to increase psychosocial and psychosexual support for CaP survivors and their partners regardless of their ethnic or cultural background. However, the content and delivery of such support should consider age disparities in CaP risk and occurrences, socio-cultural gender values and ethnic diversities in response and coping with CaP.

Acknowledgements

This study was funded by an Ulster University Vice Chancellor's Research Scholarship (PhD) to OB. The authors would like to thank all the men, partners and healthcare professionals who participated in the study. The conduct of the study was guided both by the Ulster University's Policy for the Governance of Research Involving Human Participants[39] and the Declaration of Helsinki.

Conflict of interest statement

The authors declare no conflict of interest.

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Data Availability Statement: The data that support the findings of this study are available at the Ulster University Repository and available on request from the last author. The data are not publicly available due to privacy or ethical restrictions. The study has passed ethical committee review.

List of tables

Figure legends

Table 1: Study Inclusion and Exclusion Criteria

	Inclusion	**Exclusion**
Men	BA or BC ethnic origin	BA/BC men receiving palliative care
	Undergone at least 3 months post active treatment for CaP	
	Aged 18 years and above (BA/BC men develop CaP earlier in life compared to men of other ethnic populations)	
	Resident in the UK	
	Able to read, understand and speak English	
Partners	In an intimate or marital relationship with BA or BC man who has undergone at least three months post active treatment for CaP	Partners of BA/BC men with CaP receiving palliative care
	Resident in the UK	
	Aged 18 years and above	
	Able to read, understand and speak English	
	Can be of any ethnic origin	
	Can be of any gender	
HCPs	Any health professional working as a member of the uro-oncology team (E.g. oncologists, urologists, radiographers, clinical nurse specialists, uro-oncology nurses)	Non-health professionals (E.g., support workers as they are not directly involved in both planning and delivering healthcare).

Table 2: Participants' Demographics

	Men (n=25)	Partners (n=11)	HCPs (n=11)
Gender			
Male	25	-	4
Female	-	11	7
Ethnicity			*
Black Caribbean (BC)			
Jamaica	8	2	
Barbados	4	2	
Guyana	1	-	
Montserrat	1	-	
St. Lucia	1	-	
Caribbean Virgin Islands	1	-	
Dominica	1	-	
Black African (BA)			
Nigeria	2	1	
Ghana	4	2	
Sierra Leone	2	-	
Caucasian			
White British	-	2	

White Irish	-	1	
Spanish	-	1	
Age (years)			*
< 45	-	1	
45 – 55	3	5	
56 – 65	11	2	
66 – 74	6	2	
75 and above	5	1	
Length of time since active treatment for CaP		*	*
>3 months <one year	3		
One to five years	10		
>5 years	10		
Ongoing long-term treatment	2		
Treatment type		*	*
Surgery (including robotic)	8		
Brachytherapy	5		
Radiotherapy + hormone treatment	7		
Surgery + radiotherapy	3		
Hormone treatment + chemotherapy	1		
Hormone treatment + cryotherapy	1		
Marital status			*
Married (in years)			
< 20	7	4	
21-30	3	2	
31-40	3	3	
>40	6	2	
Not specified	1	-	
With unmarried partner	3	-	
Single	1	-	
Widowed	1		
Educational qualification			*
Below graduate	13	3	
Graduate	5	4	
Post graduate	5	4	
Not specified	2	-	
Employment type			*
Skilled/professional jobs	5	4	
Semi-skilled/unskilled) jobs	5	-	
Self employed	3	2	
Retired	11	4	
Not specified	1	1	

Length of time since resident in the UK			*
< 20years	1	-	
20-30 years	7	5	
>30 years	16	5	
Not specified	1	1	
Health professional title	*	*	
Consultant Urologist			2
Consultant Oncologist			1
Consultant Radiologist			1
Uro-Oncology Nurses			4
Urology Clinical Nurse Specialist			2
Urology Trainee			1

*data not deemed applicable

Table 3: Emerged Categories and some Supporting Quotes from Study Participants

	Category	Supporting quotes
1.	**Owning the illness**	[i] *"…as a Black man, sex is quite high on the priority list…but Black men I think sexually tend to be quite private erm we struggle to even have discussion with our peers about prostate cancer, …it's a stigma sort of thing you know …" (Mr Kelvin, BC, 56)* [ii] *"…but I need to earn my money, I mean you are already taking my manliness away, taking everything away from me, you are stripping me bit by bit, right, I just thought no … cost what it will cost, I have to take charge of my life, I have to be looked up to again as a man…" (Mr Nelson, BC, 59)*
2.	**Navigating the journey through a bumpy terrain**	[i] *"…nobody wants to be sick, but when you get sick, you want to be treated with dignity and professionally, and that's completely what I got with Dr…, if you had a question…he will talk to you about it in a professional fashion…it was perfect, as good as one could expect…" (Mr Fred, BC, 62)* [ii] *"…initially I was having my treatment at …hospital, then an issue occurred between myself and one of the doctors…looking at his culture, I knew where he was coming from and I just thought no, I am not having that ..the reports that were written by this doctor, this doctor's English wasn't the best English possible and when you look at the terminologies he used, I got to tell you it was awful, it really was awful,… we put an official complaint in, they investigated, came in and apologised, they said 'yes they were insensitive words used erm and they apologised for that'…" (Mr Nelson, BC, 59)* [iii] *"…I mean this thing has really hit me …previously we could just get on with it (sex) but now I can't, and even the fact that I have to go and inject myself before I have sex, that is my headache…and sometimes injecting yourself and it is not firm enough to have sex makes it even worse, ok I am not bothered, I won't do it, but I have to remember that I am not single, I am in a relationship and sex is a big part of any relationship, so if I am being selfish with it and didn't think about the impact on my wife, I'm not being honest with myself and it is not nice, so whether I like it or not I just have to…" (Mr Ron, BA, 56)* [iv] *but er, you know with we Africans when they say you are not a man, it means ern, one thing that comes to mind is you can't have children, you see when you're not a man, you can't have children…in my own case even though I could still have some activity, you know when they remove the prostate, that's it, you know, you don't have any more semen, you see … I feel bad about it, I feel bad about it, but at least I'm alive you know…" (Mr Ellis, BA, 74)*
3.	**Partner in the passenger seat**	[i] *"…so without letting me know, he bought erm Viagra tablets a couple of times…" (Mrs Julie, BA, 62)*

		[ii] *"… I felt the burden because I am somebody that talks … you know women we talk…it's a form of healing and letting everything out, but he doesn't, the impact was the quietness, you know that he was always quiet… I don't know what is on your mind…you know the relationship wasn't that great…the sexual aspect of things went out of the window …so yea that's the main issue now because it's not easy… I ask myself is it going to be like this forever? Or is it going to correct itself? …emotionally I feel that there's something missing, and sort of when am I going to get that back…you feel a bit frustrated sometimes…" (Mrs Isabella, BA, 50)*
4.	**Healthcare Professionals recognising the difference**	[i] *"…But, what strikes me, those who I have spoken to about these alternative ways to generate an erection is that that's not palatable…my feeling is that there is a need to be naturally potent…" (HCP 1, focus group 1, consultant urologist)* [ii] *"…So, I've had men express that (sexual virility) and then in this radio phone-in, women also expressed that…So, the whole thing kind of reinforced itself… It's tied up with a kind of idea of manhood…the idea of being able to have children even though you're nearly 70, it's tied up with your position in society and how people who regard you as not being a man if they knew… because they would be seen as less of a man… the whole idea of race is tied up to your identity as a man…" (HCP 4, focus group 1, consultant urological surgeon).*
5.	**The core category: man in the driving seat**	[i] *"…because I need to be there for my family I need to be able to provide for my family …I have to, as a man, look to my family, ok, I have to, if I am not able to have that ability to provide by myself, then mentally, it is destroying me, it will destroy me…" (Mr Nelson, BC, 59)* [ii] *"…I don't think African men, I don't think they like being told because, culturally it's like they tell people what to do, they don't like being told so …" (Mrs Grace, BA, 50)* [iii] *"…it was my decision first… primarily and then she backed me up… I said there are all these various things but this is what I'm going to do… being the only son and growing up without a father you learn to take decisions, I lead even at work, so I'm quite, some people say I find it quite difficult to delegate…" (Ben, BA, 50)* [iv] *"…He very much owned his illness and didn't want to share…" (Mrs Anna, WI, 49).* [v] *"…they rarely bring their partners… I had a case scenario, a young man …he's 51 or 50, he said 'I don't want my wife to know' I said why maybe they have concerns for their wives, he said 'my wife has got high blood pressure and if she gets to know, it's going to make it worse', he said 'oh my children are doing GCSE, I don't want this to destabilise them…" (HCP 6, uro-oncology nurse)* [vi] *"…my wife I think her support is …her personal strength within herself … she is a strong-willed person and strong character and I think that those are the strengths that have driven her through this challenge…she*

		likes to do everything behind the scene kind of thing …" (Mr Harry, BC, 60) [vii] *"…er, she does not have any needs…" (Mr Dave, BA, 62)* [viii] *"…it's just sometimes I don't really want to talk about it and she (wife) is not too happy about my attitude … I probably don't know what to say…because I am not quite happy about the whole situation…but there is nothing I can do about it…" (Mr Mike, BC, 68)* [ix] "*…I tell him all the time about communication… but it's a big issue…" (Freda, BC, 66)* [x] *"… I think it's more cultural and the way families are set up … men can't show any sign of weakness or pain in front of their wives and in this particular case, it's painful mentally and everything when you think that you can't have sex when you want to have it…" (Mr Okri, BA, 58)*

'Man in the driving seat': a grounded theory study of the psychosocial experiences of Black African and Black Caribbean men treated for prostate cancer and partners

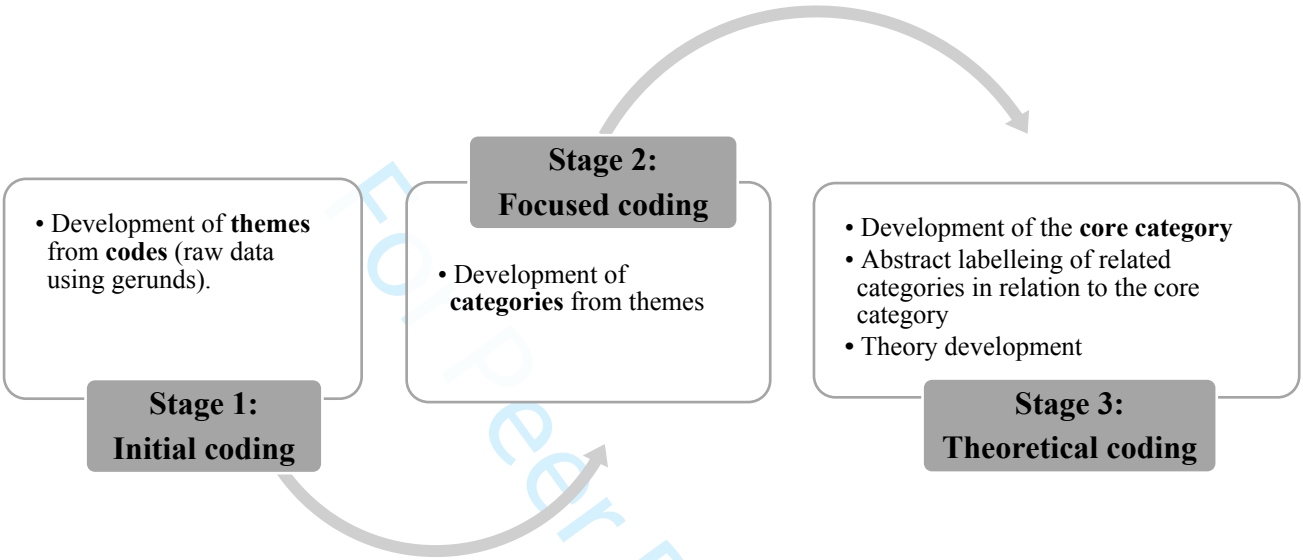

Figure 1: Stages involved in data analysis

'Man in the driving seat': a grounded theory study of the psychosocial experiences of Black African and Black Caribbean men treated for prostate cancer and partners

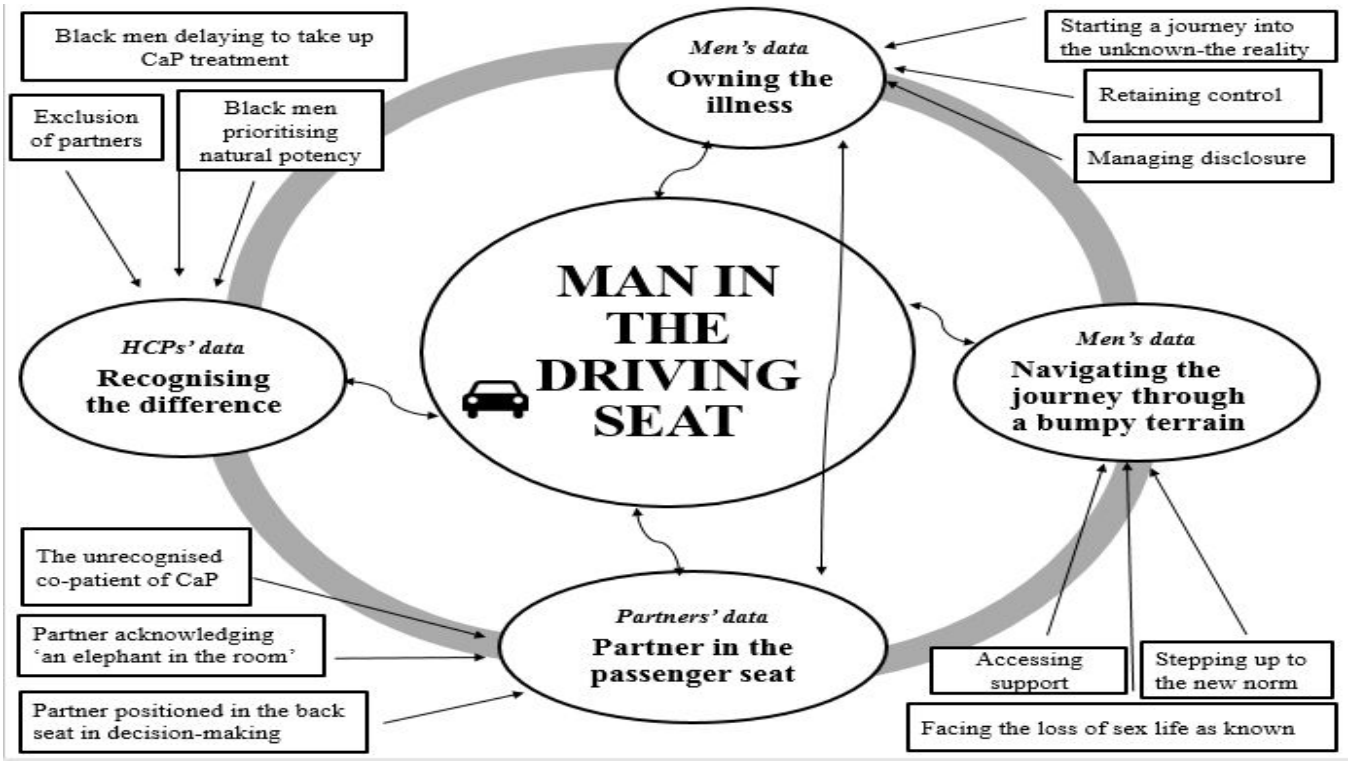

Figure 2: Theoretical model showing the core category, associated categories and their contributing themes from the men, partner and HCPs' data

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

'Man in the driving seat': A grounded theory study of the psychosocial experiences of Black African and Black Caribbean men with prostate cancer and their partners

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	5
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	1
Occupation	3	What was their occupation at the time of the study?	1
Gender	4	Was the researcher male or female?	5
Experience and training	5	What experience or training did the researcher have?	1, 5
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	5
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	5
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	4 (ref 23), 5
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	4
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	4
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	4 (ref 23)
Sample size	12	How many participants were in the study?	5
Non-participation	13	How many people refused to participate or dropped out? Reasons?	4 (ref 23)
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	5
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	5
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	5, Table 2
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	4
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	N/A
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	5
Field notes	20	Were field notes made during and/or after the inter view or focus group?	5
Duration	21	What was the duration of the inter views or focus group?	5
Data saturation	22	Was data saturation discussed?	5
Transcripts returned	23	Were transcripts returned to participants for comment and/or	N/A

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	5
Description of the coding tree	25	Did authors provide a description of the coding tree?	Fig. 1 & 2
Derivation of themes	26	Were themes identified in advance or derived from the data?	5, Fig 1.
Software	27	What software, if applicable, was used to manage the data?	5
Participant checking	28	Did participants provide feedback on the findings?	5
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Table 2, pg 6-1
Data and findings consistent	30	Was there consistency between the data presented and the findings?	10-12
Clarity of major themes	31	Were major themes clearly presented in the findings?	6-9
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	6-9

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.